Supreme Court, U.S.
FILED
SEP 1 1989
JOSEPH F. SPANIOL, JR.
CLERK

No. 88-1503

IN THE

Supreme Court of the United States

OCTOBER TERM, 1989

NANCY BETH CRUZAN, by her parents and co-guardians, LESTER L. and JOYCE CRUZAN,

Petitioners,

v.

DIRECTOR OF MISSOURI DEPARTMENT OF HEALTH, and ADMINISTRATOR OF THE MISSOURI REHABILITATION CENTER AT MT. VERNON,

Respondents,

v.

THAD C. MCCANSE, Guardian ad litem,

Respondent.

On a Writ of Certiorari to the Supreme Court of the State of Missouri

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BRIEF OF *AMICUS CURIAE* AMERICAN ACADEMY OF NEUROLOGY IN SUPPORT OF PETITIONERS

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September 1, 1989

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BRIEF OF *AMICUS CURIAE* AMERICAN ACADEMY OF NEUROLOGY IN SUPPORT OF PETITIONERS

INTEREST OF *AMICUS CURIAE*

The American Academy of Neurology (the "Academy") is a non-profit organization comprised of over 10,000 neurologists throughout the United States. Because the Missouri Supreme Court's 4-3 ruling in this case will significantly and adversely affect these physicians' medical practices, the Academy submits this brief on behalf of its members in support of the petitioners. Letters from all parties to the case below indicating their consent

to the filing of this brief have been filed with the Clerk of the Court.

Neurologists are called upon routinely to evaluate injuries to the brain and to advise patients and their families or guardians regarding appropriate medical treatment. Often, neurologists must decide swiftly in the early stages of treatment whether to recommend the use of artificial life support technologies to sustain bodily functions while they pursue specific treatment strategies. These decisions are made with the knowledge that such life support technologies can maintain a patient's bodily functions for many years after the treatment strategies have failed, and the patient has permanently lost all consciousness. Because the ruling below renders the *initial* decision to employ life support *irrevocable* in many cases, the ruling interferes with neurologists' ability to recommend certain medical procedures and with patients' and their families' ability freely to give informed consent to such procedures.

The members of the Academy are particularly concerned about the implications of the decision below for the thousands of patients, like Nancy Cruzan, with the most severe form of neurologic disability, those in a "persistent vegetative state" ("PVS patients"). In an effort to provide medical and ethical guidance to doctors in this important area, the Academy has adopted a formal statement of policy regarding the treatment of such patients. *See* American Academy of Neurology, *Position of the American Academy of Neurology on Certain Aspects of the Care and Management of the Persistent Vegetative State Patient* (Apr. 21, 1988), *reprinted in* Neurology, Jan. 1989, at 125 [hereinafter "Academy Statement"] (Appendix A).

The Academy Statement reflects careful deliberation by the Academy, thorough review of medical, ethical, and legal literature, and the extensive clinical experience of Academy members with PVS patients and their families. It is founded on the accepted principle of medical ethics that neurologists, like all physicians, have a duty to promote aggressive treatment of unconscious patients for so long as hope of recovery remains. The corollary principle mandates that when hope is gone, sound medical ethics permit neurologists to terminate all treatment, including artificial nutrition and hydration, if desired by their patients or the patients' families or guardians. Neurologists have a strong interest in practicing medicine in a manner consistent with their code of ethics, an interest severely compromised by the ruling below.

On behalf of its member neurologists, and on the basis of its stated interests, the Academy urges this Court to reverse the decision below in this critically important case.

SUMMARY OF ARGUMENT

This case involves the question of whether the family, or other representative, of a patient in a persistent vegetative state may withdraw consent for the provision of artificial nutrition and hydration through a surgically implanted gastrostomy tube. Today, more than 10,000 patients in the United States are being maintained in a persistent vegetative state. The persistent vegetative state results from severe damage to the cerebral hemispheres of the brain, which control cognitive functions. PVS patients are permanently unconscious and unable to experience emotion, sensation, or pain, and have no hope of recovery. Because PVS patients retain functioning brain stems, they are often capable of breathing on their own, but they are incapable of chewing or swallowing normally.

Artificial nutrition and hydration constitutes medical treatment for PVS patients. When a patient is incapable of chewing or swallowing, the artificial feeding process replaces these normal bodily functions. The gastrostomy tube must be surgically implanted, and the feeding proc-

ess must be closely monitored by physicians. The use of a gastrostomy tube is therefore indistinguishable from other forms of medical treatment.

The decision below requires perpetual maintenance of artificial life support for all PVS patients. The majority below failed to discuss the benefits and burdens of medical treatment for PVS patients. Instead, it assumed that all life sustaining treatment (even treatment offering no hope of recovery) is beneficial unless it is painful or physically burdensome. But treatment of PVS patients is never painful or physically burdensome for them because the ability to experience such sensations is an attribute of consciousness. Thus, the purported balancing process used by the majority below would always require ongoing treatment of PVS patients, rendering an initial decision to institute life support measures irrevocable.

The irrevocability of decisions to employ artificial life support may discourage the use of beneficial medical treatment. Doctors cannot reliably diagnose the persistent vegetative state until a patient has remained completely unconscious for a period of one to three months. During that initial period, artificial life support may be necessary to maintain the patient so that she may benefit from any recovery of cerebral cortical function. Thus, physicians normally advise patients (through the patients' surrogates) to accept artificial life support in the first instance. If a court-made rule renders that initial decision irrevocable, physicians may hesitate to employ artificial life support aggressively, and families will be far less likely to consent to treatment that could condemn their loved ones to years in a persistent vegetative state.

Furthermore, maintenance of useless and intrusive medical treatment violates principles of medical ethics. Compelled maintenance of PVS patients contravenes established principles of medical ethics that require physicians to honor patients' rights to self-determination and to strive at all times to maintain patients' dignity.

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All patients, both competent and incompetent, enjoy a constitutional right to bodily integrity, derived from the guaranties of liberty in the fifth and fourteenth amendments and from the right to privacy that underlies the Bill of Rights. In the medical treatment context, this constitutional protection takes its meaning from the common law doctrines of self-determination and informed consent and the corollary right to refuse medical treatment. Thus, a patient generally has a constitutionally protected choice of whether to initiate medical treatment. The constitutional right to bodily integrity is not affected by the fact that treatment has commenced; hence the decision to withdraw consent enjoys the same constitutional protection as the decision of whether to initiate it.

The majority below mischaracterized the state's interest in protecting life as unqualified. It therefore failed to balance the state's interest against Nancy Cruzan's fundamental interests in personal liberty and bodily integrity. Under the proper balancing test, Ms. Cruzan's interests should be upheld. The state has articulated no compelling interest in maintaining life that can exist only on a vegetative level. Nor can it show any personal interests of Ms. Cruzan that require protection by means of compelled medical treatment.

The proper approach for this Court is to defer to the decisions of the families (or other representatives) of PVS patients to initiate, continue, or terminate medical treatment. By fashioning a rule of deference to the decisions of patients' families, as informed by the medical profession, this Court will uphold Nancy Cruzan's constitutional rights to personal liberty and bodily integrity and avoid embarking on a course of medical rulemaking.

ARGUMENT

I. THE DECISION BELOW INTERFERES WITH PHYSICIANS' ABILITY TO CARE AGGRESSIVELY FOR UNCONSCIOUS PATIENTS WHILE HOPE OF RECOVERY REMAINS AND REQUIRES CONTINUED TREATMENT AFTER HOPE NO LONGER EXISTS

A. Patients in the Persistent Vegetative State Present Unique Medical Circumstances, and Artificial Nutrition and Hydration Constitutes Medical Treatment for Them

It is estimated that more than 10,000 patients—like Nancy Cruzan—are being maintained in a persistent vegetative state in the United States today, and the number will increase significantly in the near future.[1] These patients are the unfortunate product of advances in medical technology over the past 20 years. Increased use of various therapeutic measures such as cardiopulmonary resuscitation, which until recently were either unknown or not widely practiced, represents an important medical advance. Through these techniques, patients who suffer a cessation of respiratory and perhaps cardiac function can, at times, be restored to physical life. Many such patients are rescued from the brink of death and restored to meaningful life. But PVS patients cannot be restored. PVS patients are a specific, clearly identifiable class of patients who, while not brain dead, have sustained massive and permanent brain damage and a complete loss of consciousness from which there can be no recovery. The persistent vegetative state is the most complete and severe form of neurologic disability.

PVS patients are totally and permanently unconscious and devoid of thought, emotion, and sensation. The Academy defines the persistent vegetative state as "a form of eyes-open permanent unconsciousness in which the patient has periods of wakefulness and physiological sleep/wake cycles," but in which the patient is at all times totally unaware of herself or her environment. Academy Statement § I. (App. A at 1a). This condition results when a person suffers severe damage to the cerebral hemispheres of the brain, which control the "'thinking' functions," but retains a functioning brain stem, which controls reflexive functions. *See* President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* 175 (1983) [hereinafter "President's Commission"]. Thus, PVS patients exposed to certain stimuli may exhibit reflexive responses including grimacing, swallowing, unfocused eye movement, and pupillary response to light. *Id.* However, the loss of all cerebral cortical functions means that "[p]ersonality, memory, purposive action, social interaction, sentience, thought, and even emotional states are gone . . . as are joy, satisfaction, and pleasure." *Id.* at 174-75, 181-82.

Because PVS patients retain an intact brain stem, they generally do not lose their capacity to breathe, a reflexive function. But they do lose their ability to chew and swallow in a normal manner, a cognitive function. Academy Statement § I.A. (App. A at 1a). Accordingly, a respirator is generally not needed for life support of PVS patients, but artificial nutrition and hydration are necessary.

The attempt of the majority below to characterize the ongoing provision of nutrition and hydration through a gastrostomy tube as routine care and not medical treatment is not supported by legal, medical, or ethical precedent, and contradicts practical medical reality. The court below recognized the finding in *Quinlan* that Karen Quinlan's respirator was medical "treatment . . . so extraor-

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[1] Cranford, *The Persistent Vegetative State: The Medical Reality (Getting the Facts Straight)*, Hastings Center Rep., Feb./March 1988, at 27, 31.

dinary and so invasive that the state's interest paled in comparison." *Cruzan v. Harmon*, Petitioner's Appendix at A30 (citing *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976)). However, it distinguished artificial feeding through a gastrostomy tube from medical treatment, such as the use of a respirator. Pet. App. at A34-A37. The medical community finds no basis for distinguishing between the two procedures in terms of their status as medical treatment. In each case, as a result of an illness or traumatic injury, the body loses the ability to perform certain functions on its own and an artificial device takes over. If a patient cannot breathe, air is pumped in through a respirator; if a patient cannot swallow, fluids and nutrition are administered through a surgically implanted tube. Both devices replace normal bodily functions which are compromised by the illness. Both are medical treatment.

The gastrostomy tube must be surgically implanted with prior, written consent. After surgery, a pre-mixed solution of nutrients is administered to the patient through the tube. Although nurses perform the relatively uncomplicated procedure of administering the solution, the life support process requires continual and careful monitoring by a physician. All learned medical and medico-ethical organizations agree that provision of nutrition and hydration through such a tube is a medical treatment that a patient has a right to forgo.[2] Likewise, most higher courts that have considered the status of

[2] Academy Statement §§ II., III. (App. A at 2a-6a); American Medical Association, *Withholding or Withdrawing Life-Prolonging Medical Treatment*, Current Opinions of the Council on Ethical and Judicial Affairs, Opinion 2.18 (1986) ("[l]ife prolonging medical treatment includes medication and artificially or technologically supplied respiration, nutrition or hydration"); Hastings Center, *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying* 59-62 (1987); President's Commission, *supra* p. 7, at 190; U.S. Congress, Office of Technology Assessment, *Life-Sustaining Technologies and the Elderly*, OTA-BA-306, at 275-329 (1987).

artificial nutrition and hydration have determined it to be medical treatment. *See, e.g., McConnell v. Beverly Enterprises-Connecticut, Inc.*, 209 Conn. 692, 705, 553 A.2d 596, 603 (1989) ("[t]he applicable case law has by and large concluded that . . . there is no logical distinction between removal of a respirator and removal of a gastrostomy tube") (and cases cited therein). The majority's contrary conclusion below is both opposed to established medical practice and offensive to good medical ethics.

B. The *Cruzan* Majority's Ruling Requires the Perpetual Maintenance of Artificial Life Support for Patients Who Have Lapsed Into a Persistent Vegetative State and Therefore, by Definition, Have No Hope of Recovery

PVS patients are incapable of feeling pain or otherwise suffering because such sensations are attributes of consciousness requiring cerebral cortical functioning that these patients lack. Academy Statement § I.D. (App. A at 2a). Given this aspect of the persistent vegetative state, the interpretation and application by the majority below of the right to refuse medical treatment *precludes entirely* the withdrawal of artificial nutrition and hydration from a PVS patient until death occurs from other causes.

The *Cruzan* majority grudgingly conceded that a federal, constitutional privacy-based right to refuse treatment might exist.[3] It then purported to balance the individual's interest in exercising this right against the state's asserted interest in the preservation of all biological life, even if devoid of human consciousness. The majority concluded that the state's interest will always

[3] Pet. App. at A21-A25. The majority also recognized a qualified common law right to refuse treatment grounded on the doctrine of informed consent, and included that right among the interests of the patient that it weighed against those of the state. *Id.* at A20-21, A25, A29.

supersede the individual's rights unless (if ever) continued treatment is painful or imposes some other burden on the patient. Finding that the continued supply of nutrients and fluids through a tube surgically implanted in Nancy Cruzan's stomach did not impose any burden on her, the majority held that the state's interest prevailed, and artificial life support must continue.[4]

As applied to PVS patients, the majority's "balancing" process is a meaningless exercise because it fails to consider whether treatment confers any benefit. The majority below assumed that maintenance in a PVS condition is beneficial. This reasoning, combined with the holding that the medical treatment at issue is not burdensome, mandates maintenance of all PVS patients.

As explained above, continued medical treatment of *any* kind can *never* be painful or physically burdensome to a PVS patient because the patient lacks the cognitive capacity to experience such sensations. Hence, the *Cruzan* majority's reasoning dictates that artificial life support, once initiated for a PVS patient, must be continued indefinitely in all cases. Such support may be discontinued only when some other physiological breakdown occurs —perhaps only after many years—that neither the support system in place nor other medical procedures can remedy.[5]

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[4] *Id.* at A36-A37 (central issue "is whether feeding and providing liquid to Nancy is a burden *to her*") (emphasis in original); *id.* at A38 ("[g]iven the fact that Nancy is alive and that the burdens of her treatment are not excessive for her, we do not believe her right to refuse treatment . . . outweighs the [state's interest in preserving her life]").

[5] There was medical testimony in the trial court that Nancy, who was then only 30 years old, could live as long as 30 years in the same vegetative state if the artificial nutrition and hydration were continued. *Id.* at A8, A26, A38. In fact, the Academy submits, Nancy Cruzan can be expected to continue to exist for some years, or even decades.

C. The Irrevocability of an Initial Decision to Employ Artificial Life-Support Technologies Will Discourage Their Use in the First Instance, Thus Endangering Patients' Lives and Violating Accepted Principles of Medical Ethics

Until an unconscious patient is reliably diagnosed as being in a persistent vegetative state, the prognosis for recovery of cerebral cortical functions is uncertain. The diagnosis of PVS usually cannot be made with medical certainty "until the patient's complete unconsciousness has lasted a prolonged period—usually one to three months . . . ." Academy Statement § IV.A. (App. A at 6a). A physician's ethical duty aggressively to seek to cure patients while there is still hope of recovery dictates that a physician treating an unconscious patient urge the patient to accept (through her family or legal representative) artificial life support. Artificial life support measures, including gastrostomy feeding, ensure that the patient will benefit from any spontaneous recovery of consciousness or from successful medical treatment. At present the advice to initiate such measures is ordinarily followed.

But such advice is less likely to be either given or heeded if, as the *Cruzan* majority's holding requires, the initial decision to employ artificial life support is irrevocable. Because of an understandable desire to avoid the considerable risk that such authorization will condemn the patient to years of PVS status, physicians may hesitate to recommend, and families will be much less likely to authorize, artificial nutrition and hydration for patients whose prognosis is grim but not hopeless. As one court stated, "[s]uch a rule [of irrevocability] could discourage families and even doctors from even attempting certain types of care and could thereby force them into hasty and premature decisions to allow a patient to die." *In re Conroy*, 98 N.J. 321, 370, 486 A.2d 1209, 1234

(1985).[6] Thus, the *Cruzan* majority's rule not only would frustrate the practice of ethical medicine,[7] but ultimately would undermine the state's asserted interest in preserving life.

It may be possible to interpret *Cruzan* so as to avoid this result, but doing so would create an even worse nightmare. The state might attempt to preclude doctors and families from taking irrevocability into account during discussions of early treatment by compelling them to employ all available means of artificial life support in the first instance to protect its asserted unqualified interest in life. Given the majority's conclusion that the state's interest always outweighs the patient's rights where treatment imposes no burden (of the sort recognized by the majority), the majority's reasoning usually would sustain such state compulsion. However, the result—forced irrevocable artificial support for all patients under all circumstances—is clearly incompatible with the principles of personal liberty and bodily integrity inherent in the fourteenth amendment. *See* Section II *infra.*

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[6] *See also Brophy v. New England Sinai Hosp., Inc.*, 398 Mass. 417, 438, 497 N.E.2d 626, 638 (1986); Lynn & Childress, *Must Patients Always Be Given Food and Water?*, Hastings Center Rep., Oct. 1983, at 17, 20; Academy Statement § IV.C. (App. A at 7a).

[7] Numerous state courts have relied on principles of medical ethics to guide them in cases concerning PVS patients. *See Rasmussen v. Fleming*, 154 Ariz. 207, 217, 741 P.2d 674, 684 (1987) (en banc); *Bouvia v. Superior Court*, 179 Cal. App. 3d 1127, 1141, 225 Cal. Rptr. 297, 303-04 (1986); *In re Gardner*, 534 A.2d 947, 954 (Me. 1987); *Brophy*, 398 Mass. at 439, 497 N.E.2d at 638; *In re Jobes*, 108 N.J. 394, 417, 529 A.2d 434, 446 (1987); *In re Peter*, 108 N.J. 365, 381-82, 529 A.2d 419, 427-28 (1987); *In re Farrell*, 108 N.J. 335, 350-51, 529 A.2d 404, 411-12 (1987); *In re Guardianship of Grant*, 109 Wash. 2d 545, 554-55, 747 P.2d 445, 450 (1987) (en banc), *modified*, 757 P.2d 534 (1988).

D. The Requirement That Physicians Provide Useless and Unwanted Medical Treatment to PVS Patients Is Fundamentally at Odds Both With Principles of Medical Ethics and With an Accurate Assessment of the Benefits and Burdens of Such Treatment

A physician's duty aggressively to promote the well-being of a patient presumes that some chance of improvement or recovery remains. However, the *Cruzan* majority held that artificial life support must be maintained even after hope is lost, apparently on the assumption that physicians still have the duty to "care": "[W]hen we permit ourselves to think that care is useless if it preserves the life of the embodied human being without restoring cognitive capacity, we fall victim to the old delusion that we have failed if we cannot *cure* and that there is, then, little point to continue care." Pet. App. at A36 (citation omitted) (emphasis in original).

In the context of a PVS patient's existence, "care" may have symbolic meaning for the caregiver, the family, and society, but it has no meaning for the patient. The patient cannot understand or even perceive her care, much less be comforted by it. Therefore, she cannot be regarded as benefitting from care in any meaningful sense. Hence, ethical principles recognize that where the family, speaking for the patient, feels that "care" has become a euphemism for the meaningless prolongation of vegetative life, the physician has no contrary duty to maintain such care. Academy Statement §§ II.A., III. (App. A at 2a-5a); American Medical Association, *supra* note 2.

Moreover, a physician's ethical duty is not to preserve life or well-being at all costs, but rather to do so in a manner consistent with the patient's right to self-determination. *See* Academy Statement § II.D.1. (App. A at 4a) ("The recognition of a patient's right to self-determination is central to the medical, ethical, and legal principles relevant to medical treatment decisions."). Hence, state-compelled maintenance of useless and un-

desired artificial life support for PVS patients not only directly infringes upon the patient's constitutional guarantee of fundamental liberty, but it does so in a manner that interferes with physicians' ethical responsibility to avoid harming the dignity of their patients. The *Cruzan* majority ignored the established principle of medical ethics that, "[a]t all times, the dignity of the patient should be maintained." [8] In the process, it withheld from Nancy Cruzan a core aspect of humanity by requiring her and many others sharing her misfortune to be kept "alive" for years to come in an undignified vegetative state. As recounted in the Petition for Certiorari, Nancy Cruzan

> is completely dependent upon others for care. Her body is stiff and so severely contracted that her fingernails cut into her wrists. Her face is red, puffy and swollen, and she drools on herself. She is missing teeth. Her bathing, oral care and personal feminine hygiene, including menses, are cared for by others. She must be turned every few hours to prevent bedsores.

Petition for Writ of Certiorari at 5 (citation omitted).

The discussion of patient's dignity highlights the need for families (or other surrogates) to consider the benefits and burdens of a course of treatment free from state interference. The undignified state in which a patient is maintained constitutes one burden imposed by the treatment. That burden should be balanced against the

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[8] American Medical Association, *supra* note 2. Furthermore,

> [i]n deciding whether the administration of potentially life-prolonging medical treatment is in the best interest of the patient who is incompetent to act in his behalf, the physician should determine what the possibility is for extending life *under humane and comfortable conditions* and what are the prior expressed wishes of the patient and attitudes of the family or those who have responsibility for the custody of the patient.

Id. (emphasis added).

benefits that the treatment might provide. Indeed, much medical treatment arguably places the patient in an undignified condition, but the benefits conferred on the patient render the indignities tolerable. However, in the case of PVS patients the only conceivable benefit of treatment is to maintain the status quo. As another high state court realized, in such circumstances

> the burden of maintaining the corporeal existence degrades the very humanity it was meant to serve. . . . The duty of the State to preserve life must encompass a recognition of an individual's right to avoid circumstances in which the individual himself would feel that efforts to sustain life demean or degrade his humanity.

Brophy v. New England Sinai Hosp., Inc., 398 Mass. 417, 434, 497 N.E.2d 626, 635 (1986).

By insisting on the preservation of life at all costs and regardless of the benefits and burdens of compelled medical treatment, the decision below prevents physicians from taking into account patients', their families', and society's interests in maintaining dignity. Indeed, the decision completely removes physicians from the decision-making process once the treatment has begun. It thus precludes physicians from "caring" for their PVS patients in the only way that "care" has any meaning once the PVS diagnosis has been confirmed.

II. THE COURT SHOULD LEAVE THE DECISION WHETHER TO INITIATE OR CONTINUE MEDICAL TREATMENT OF A PVS PATIENT TO THE PATIENT'S FAMILY AS INFORMED BY THE TREATING PHYSICIAN

As is apparent from the foregoing, the role of the courts in the case of PVS patients should be extremely limited. In general, courts should leave medical treatment decisions in such cases to the patient's family (or other representative) and the patient's physician. In particular, appropriate deference should be paid to the

considered ethical positions of the medical profession. The courts should step in, we submit, only under limited circumstances, such as where there is disagreement among the parties directly involved, or where court action is necessary to carry out the wishes of the patient's surrogate to initiate, continue, or terminate treatment as informed by competent medical advice from the treating physician.

A. The Constitutionally Protected Rights of Personal Liberty and Bodily Integrity and the Related Common Law Doctrine of Informed Consent Require That When Consent Is Withdrawn Treatment Must Cease

Under the Constitution, individuals enjoy the right to be free from unwanted physical invasions, including unwanted medical care. This right derives from the Due Process Clauses of the fifth and fourteenth amendments and is an aspect of the right to privacy contained in the notions of personal liberty that are the core of the Bill of Rights. *United States v. Charters*, 829 F.2d 479, 491 (4th Cir. 1987) (and cases cited therein); *Gray v. Romeo*, 697 F. Supp. 580, 585 (D.R.I. 1988). In the medical treatment context, this constitutional interest takes its meaning from the common law doctrine of self-determination and the right of informed consent with its corollary right to refuse treatment. At issue here is the intensely personal decision of Nancy Cruzan's parents, aided by the advice of her treating physician, to exercise this fundamental right on her behalf by discontinuing artificial feeding and hydration that can serve no useful purpose, as they know she would have wanted. That decision is closely analogous to the highly personal decision of married couples as to whether to have children, which *Griswold v. Connecticut*, 381 U.S. 479 (1965) holds is beyond state control.[9]

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[9] Family decisions concerning the medical treatment of an incompetent family member closely resemble decisions in the areas of " 'marriage, procreation, contraception, family relationships, and child rearing and education' " that are constitutionally protected from government interference. *See Carey v. Population Services Int'l*, 431 U.S. 678, 685 (1977) (citations omitted); *see also Parham v. J.R.*, 442 U.S. 584, 602-04 (1979) (recognizing parents' power to make medical decisions on behalf of their children).

The right of privacy, the "right to be let alone," as Justice Brandeis eloquently said, is the "most comprehensive of rights and the right most valued by civilized men." *Olmstead v. United States*, 277 U.S. 438, 478 (1928) (dissenting opinion).[10] The Court has frequently recognized the constitutional interest in bodily integrity, forbidding governmentally compelled medical procedures. *See, e.g., Winston v. Lee*, 470 U.S. 753 (1985) (holding that surgery on a criminal defendant could not be compelled to remove a bullet to be used as evidence in his prosecution); *Rochin v. California*, 342 U.S. 165, 172 (1952) (it "shock[ed] the conscience" that a state had forcibly pumped a suspect's stomach to remove swallowed narcotics); *Skinner v. Oklahoma*, 316 U.S. 535 (1942) (invalidating mandatory sterilization for habitual criminals); *see also Union Pac. Ry. v. Botsford*, 141 U.S. 250, 251 (1891) ("No right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person . . . .").[11] Here the right of privacy is subsumed within the liberty guaranteed by the due process clauses of the fifth and fourteenth amendments.

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[10] *See also* Warren & Brandeis, *The Right to Privacy*, 4 Harv. L. Rev. 193 (1890). The *Olmstead* decision, which did not uphold the right to privacy, was subsequently overruled by *Katz v. United States*, 389 U.S. 347 (1967).

[11] The recognition by this Court of a right to bodily integrity and the common law origins of the doctrine of informed consent demonstrate that the right to be free from compelled medical treatment is "deeply rooted in this nation's history and tradition." *Bowers v. Hardwick*, 478 U.S. 186, 192 (1986) (quoting *Moore v. City of*

The right to refuse medical treatment is basic and fundamental. Thus, competent patients generally have the right to refuse or discontinue any medical treatment, including artificial feeding and hydration. *See, e.g., Bouvia v. Superior Court*, 179 Cal. App. 3d 1127, 1137, 225 Cal. Rptr. 297, 300 (1986) (upholding the right of a competent quadriplegic patient who was in severe pain to refuse artificial feeding even though the decision would result in her death). The same rights extend to PVS patients. *See Gray v. Romeo*, 697 F. Supp. 580, 586 (D.R.I. 1988); *Brophy*, 398 Mass. at 432-34, 497 N.E.2d at 634-35; *In re Jobes*, 108 N.J. 394, 420, 429 A.2d 434, 447 (1987). The right to refuse medical treatment exists even if its exercise creates a "life threatening condition." *Bouvia*, 179 Cal. App. 3d at 1137, 225 Cal. Rptr. at 300; *see also Tune v. Walter Reed Army Medical Hosp.*, 602 F. Supp. 1452, 1454 (D.D.C. 1985); *In re Farrell*, 108 N.J. 335, 348, 529 A.2d 404, 410 (1987).[12]

East Cleveland, 431 U.S. 494, 503 (1977) (plurality opinion)). Similarly, this right is "implicit in the concept of ordered liberty." *Bowers*, 478 U.S. at 191 (quoting *Palko v. Connecticut*, 302 U.S. 319, 325 (1937), *overruled on other grounds, Duncan v. Louisiana*, 391 U.S. 145 (1968)). Thus, this case does not involve the recognition of a new fundamental right. *Cf. Michael H. v. Gerald D.*, 109 S. Ct. 2333 (1989) (refusing to accord constitutional protection to the relationship between a natural father and a child born following the mother's marriage to another man); *Bowers*, 478 U.S. 186, 191 (refusing to recognize a privacy-based fundamental right of adults to engage in consensual homosexual sodomy). Rather, it involves the application of an established fundamental right.

[12] Of the few cases overriding refusals of medical treatment, most are readily distinguishable. They generally involve religious objections to treatment, and are otherwise factually distinguishable. Moreover, the treatment ordered would generally have a beneficial life-restoring effect, an effect that is not present here.

Perhaps the most celebrated of these cases is *Application of President & Directors of Georgetown College, Inc.*, 331 F.2d 1000, *cert. denied*, 377 U.S. 978 (1964). After an emotional hearing at the hospital, the late Judge J. Skelly Wright ordered blood transfusions for a young Jehovah's Witness woman who had a seven-

A patient's incompetence does not deprive her of the right to bodily integrity. Thus, where a patient is incompetent to give or refuse consent to treatment, a family member, guardian, or other surrogate is permitted to enforce the patient's right to decide whether to consent to initiate, continue, or terminate treatment. *Gray*, 697 F. Supp. at 587; *In re Jobes*, 108 N.J. at 420, 529 A.2d at 447; *see also Thompson v. Oklahoma*, 108 S. Ct. 2687, 2693 n.23 (1988) (plurality opinion) (those who are irreversibly ill retain rights that are only meaningful if exercised by agents acting with the best interests of their principals in mind). Accordingly, in the present case the hospital sought and received the consent of Nancy Cruzan's husband and father before surgically inserting the gastrostomy tube. *Cf.* Hastings Center, *supra* note 2, at 61 ("[a]ll invasive procedures for supplying nutrition and hydration . . . should be considered procedures that require the patient's or surrogate's consent").

The rights of personal liberty and bodily integrity would be meaningless unless they extended throughout the entire course of treatment. Patients and their surrogates are not suddenly eliminated from the decision-making process because treatment has commenced. Rather, a competent patient (or the surrogate of an incompetent one) has

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month old infant. Several factors influenced his decision. First, the patient's competence was in doubt given her medical condition. Second, she seemed to be amenable to treatment if it was ordered. Third, her consent to go to the hospital contradicted her refusal to accept treatment. Fourth, the treatment she refused was a simple procedure deemed medically appropriate by her physicians. None of these circumstances is involved here.

Moreover, these cases ordering treatment contrary to a person's religious beliefs would seem to violate the right of religious free exercise guaranteed by the first and fourteenth amendments, as well as the constitutional rights to privacy and liberty of the person. *See, e.g., Holmes v. Silver Cross Hosp.*, 340 F. Supp. 125, 130 (N.D. Ill. 1972).

the right to withdraw consent once treatment has begun. The majority below ignored this fact, differentiating between the initiation of treatment—for which Nancy Cruzan's doctors were required to obtain consent—and the discontinuation of treatment—which it held was unlawful. Pet. App. at A34.

The medical community agrees that there is no supportable analytical distinction—medical, ethical, or legal—between the decision whether to initiate treatment and the decision whether to continue treatment once it has begun.[13] The *Cruzan* majority's attempt to distinguish between the initial insertion of the tube (which it considered medical treatment) and the ongoing use of the tube (which it described as "not heroically invasive") is insupportable. Pet. App. at A34. A continued course of treatment intrudes no less into the patient's bodily integrity than the initial application of the treatment. In fact, continuations of treatment may sometimes prove more burdensome.

> Whether a particular treatment will have positive effects is often highly uncertain before the therapy has been tried. If a trial of therapy makes clear that it is not helpful to the patient, this is actual evidence (rather than surmise) to support stopping because the therapeutic benefit that earlier was a possibility has been found to be clearly unobtainable.

President's Commission, *supra* p. 7, at 76; *see also Brophy*, 398 Mass. at 435, 497 N.E.2d at 636 (maintenance of a PVS patient for several years is intrusive as a matter of law). Hence, the termination of treatment requires no greater legal justification than does the constitutionally protected decision of whether to initiate it in the first place.

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[13] *See* President's Commission, *supra* p. 7, at 73-77; Academy Statement § IV.B-C. (App. A at 6a-7a).

B. The State's Asserted "Unqualified" Interest in the Life of PVS Patients In Fact Is Not Unqualified, Nor Does It Correspond to Any Attributes of Human Life That Require State Protection

The recognition by a bare majority of the Missouri Supreme Court of an "unqualified" state interest in life is at odds with Missouri law and cannot be supported under the fourteenth amendment. In several areas, Missouri's asserted interest in life yields to other state interests. The state's interest in sustaining life might not extend to the circumstance where the patient is in pain or otherwise physically burdened. *See Cruzan*, Pet. App. at A38. In addition, where a patient has signed a "living will" that complies with the Missouri living will statute, the state's interest in life gives way to the patient's decision to terminate or refuse treatment. Mo. Rev. Stat. § 459.010 *et seq.* (1986).[14] Decisions to allocate state resources, such as Medicaid funding policies, impact (and may shorten) the lives of individuals who are denied state funds.[15] Finally, as was noted by Justice Blackmar, Missouri's use of capital punishment "demonstrates a relativity of values by establishing the proposition that some lives are not worth preserving." *Cruzan*, Pet. App. at A49 (Blackmar, J., dissenting). Thus, the state has recognized that a number of other interests may outweigh its own interest in preserving life.

Because the state's interest in life is qualified, it must be balanced against the patient's compelling interest in

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[14] Missouri's Living Will Statute arbitrarily distinguishes between artificial hydration and nutrition and other forms of medical treatment. Mo. Rev. Stat. § 459.010(3). This dichotomy departs from the overwhelming medical judgment as to the definition of treatment. *See* Part I.A. *supra*.

[15] Indeed, by expending approximately $130,000 per year to maintain Nancy Cruzan, the state of Missouri may be diverting resources that are necessary to maintain the lives of patients with hope of some sort of recovery.

her rights to personal liberty and bodily integrity. The state's interest diminishes and Ms. Cruzan's right to privacy increases as her prognosis dims, rendering her medical treatment a useless intrusion. *See Quinlan*, 70 N.J. at 41, 355 A.2d at 664. The state cannot demonstrate that it has any interest worthy of overriding Nancy Cruzan's own right to bodily integrity. Where a patient retains any attribute of humanity, including any degree of consciousness or sentience, the state might reasonably assert an interest in protecting that attribute. But the state cannot reasonably assert a compelling interest in maintaining life that exists on a purely vegetative level—the only level on which a PVS patient exists. *See In re Peter*, 108 N.J. 365, 380, 529 A.2d 419, 427 (1987). ("[We] find it difficult to conceive of a case in which the state could have an interest strong enough to subordinate a patient's right to choose not to be artificially sustained in a persistent vegetative state.").[16]

The majority below based its decision in part on a refusal to engage in considerations of the "quality" of a patient's life, stating, "Were quality of life at issue, persons with all manner of handicaps might find the state seeking to terminate their lives. Instead, the state's interest is in life; that interest is unqualified." *Cruzan*, Pet. App. at A29. This reasoning ignored the facts of this case and the need to balance the state's interest against Ms. Cruzan's fundamental interest in bodily integrity. PVS patients have moved beyond the stage of existence where discussion of the quality of life has any meaning.[17] Thus, the majority below should have con-

[16] Some members of this Court have recently stated that a state may have a protectable interest in potential life, such as that represented by a human fetus. *Webster v. Reproductive Health Services*, 57 U.S.L.W. 5023, 5030 (1989) (plurality opinion). Such an interest would not apply to the PVS patient, who does not have any potential for future life except in the vegetative sense.

[17] It may well be true that for patients who retain any degree of consciousness or sentience, or for whom there is some hope of

sidered the unique circumstances of PVS patients and balanced the competing interests in preserving life and liberty.

Missouri cannot support its assertion that it has an unqualified interest in preserving life by characterizing its interest as one that the patient would assert if she could. This Court should reject any presumption by the state that a PVS patient would prefer to be sustained in that condition rather than to be permitted to die naturally as the result of the trauma causing the PVS condition. The facts of this case mandate rejection of such a presumption. First, the trial court found that Ms. Cruzan would not have wanted to be maintained in a PVS condition. *Cruzan*, Pet. App. at A60 (Higgins, J., dissenting). Second, her family, which has the authority to consent to her medical treatment, has also expressed the view that her life should not be continued in a persistent vegetative state. Third, the state can articulate no personal interest of Ms. Cruzan's that would be furthered by continuing her treatment. It cannot seriously be argued that *anyone* would choose to be sustained for years in a condition similar to Nancy Cruzan's with absolutely no hope of even reviving, much less recovering. To the extent that the state's interest in life reflects a desire to protect the patient's own interest, that interest is a nullity in the case of the PVS patient.

It should be stressed that the issue in this case is the right of a patient or her surrogate to refuse medical treatment that offers no hope of recovery. This case does not involve any form of euthanasia or "mercy killing." Without the insertion of the gastrostomy tube, Nancy

revival or recovery, the state is correct to avoid subjective considerations of the quality of such patients' lives. But such considerations are not at issue in this case. PVS patients constitute a clearly identifiable class of patients and are categorically different from all other individuals, including those with the most severe handicaps.

Cruzan would have died as the result of her accident. Her family has withdrawn the consent it initially gave for the insertion of the tube. If artificial nutrition and hydration is discontinued, the accident (which rendered Nancy Cruzan permanently incapable of chewing or swallowing) will be the true cause of her death.[18] *See Gray*, 697 F. Supp. at 587. Hence, the apparent concern of the majority below that honoring Nancy Cruzan's right to refuse treatment could lead to state-condoned mercy killing of patients with disabilities was misplaced.[19]

C. This Court Should Not Embark on a Process of Medical Rulemaking, But Should Leave the Decision of Whether to Withdraw Treatment From a PVS Patient to the Patient's Family or Other Surrogate

By reversing the holding below and leaving the decision of when to discontinue gastrostomy treatment of PVS patients in the hands of families or other surrogates, as informed by medical diagnoses, this Court will uphold patients' rights of personal liberty and bodily integrity while avoiding the process of medical rulemaking and line-drawing that otherwise would be required by this case and the flood of cases that would follow.

This Court should avoid formulating medical policy on a purported constitutional basis, or it will risk becoming

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[18] If artificial nutrition and hydration is discontinued, Nancy Cruzan will die of dehydration within about 30 days, and probably within one to two weeks. She will not starve to death. Due to the nature of the PVS condition, she will not experience pain or suffer in any way, nor will she manifest significant physical indications of the dying process. Some drying of her mouth and skin may be expected, and can easily be relieved by moisturizing the affected areas. Such care would be performed for the benefit of the family —Nancy would continue to have no awareness of her condition.

[19] Respondents have not put forth any evidence that holdings by other state courts honoring a family's decision to withdraw nutrition and hydration from a PVS patient have led to such a result.

an "*ex officio* medical board with powers to approve or disapprove medical . . . practices and standards throughout the United States." *Planned Parenthood v. Danforth*, 428 U.S. 52, 99 (1976) (White, J., dissenting). In the present case, this Court should defer to family judgments. Any other holding would require this Court and other federal and state courts to answer medical questions such as precisely what constitutes medical treatment,[20] what constitutes a terminal illness, and whether certain courses of treatment are "extraordinary measures."[21] The answers to these questions are akin to "a web of legal rules . . . resembling a code of legal regulations rather than a body of constitutional doctrine." *Webster*, 57 U.S.L.W. at 5030 (opinion of Rehnquist, C.J., White and Kennedy, JJ.). Such constitutional rulemaking has been criticized by members of this Court. *Id.* Furthermore, any conclusions that this Court might reach concerning medical issues during its 1989 term might be undercut by rapidly changing technology. *Cf. City of Akron v. Akron Center for Reproductive Health*, 462 U.S. 416, 454 (1983) (O'Connor, J., dissenting); *Brophy*, 398 Mass. at 438 n.33, 497 N.E.2d at 637 n.33 ("what was viewed as extraordinary care ten years ago might be considered ordinary care today").

The role of the courts should be limited to protecting the patient's fundamental rights, grounded in the fifth and fourteenth amendments to the Constitution, to preserve her personal liberty and bodily integrity and to

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[20] The *Cruzan* majority refused to accept that artificial nutrition and hydration constitutes medical treatment. It stated, "common sense tells us that food and water do not treat an illness, they maintain a life." *Cruzan*, Pet. App. at A34-A37. This "common sense" view simply ignores all informed medical and medico-ethical opinion. *See* Section I.A. *supra*.

[21] *See Brophy*, 398 Mass. at 437, 497 N.E.2d at 637 (the distinction between ordinary and extraordinary care is a factor to be considered).

refuse either the initiation or the continuation of unwanted treatment. The patient must be free to exercise her right—or to have that right exercised for her by her family or other surrogate—based on the advice of her physician, whose profession it is to determine what treatment options, if any, would promote the well-being of the patient.

CONCLUSION

For the foregoing reasons, and for those stated in the briefs for the petitioners and other supporting *amici*, the decision below should be reversed.

Respectfully submitted,

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September 1, 1989

APPENDIX A

APPENDIX A

POSITION OF THE AMERICAN ACADEMY OF NEUROLOGY ON CERTAIN ASPECTS OF THE CARE AND MANAGEMENT OF THE PERSISTENT VEGETATIVE STATE PATIENT *

Adopted by the Executive Board,
American Academy of Neurology,
April 21, 1988, Cincinnati, Ohio

I. The persistent vegetative state is a form of eyes-open permanent unconsciousness in which the patient has periods of wakefulness and physiological sleep/wake cycles, but at no time is the patient aware of him- or herself or the environment. Neurologically, being awake but unaware is the result of a functioning brainstem and the total loss of cerebral cortical functioning.

A. No voluntary action or behavior of any kind is present. Primitive reflexes and vegetative functions that may be present are either controlled by the brainstem or are so elemental that they require no brain regulation at all.

Although the persistent vegetative state patient is generally able to breathe spontaneously because of the intact brainstem, the capacity to chew and swallow in a normal manner is lost because these functions are voluntary, requiring intact cerebral hemispheres.

B. The primary basis for the diagnosis of persistent vegetative state is the careful and extended clinical observation of the patient, supported by laboratory studies. Persistent vegetative state patients will show no behavioral response whatsoever over an extended period of

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* Reprinted in Neurology, Jan. 1989, at 125.

time. The diagnosis of permanent unconsciousness can usually be made with a high degree of medical certainty in cases of hypoxic-ischemic encephalopathy after a period of 1 to 3 months.

C. Patients in a persistent vegetative state may continue to survive for a prolonged period of time ("prolonged survival") as long as the artificial provision of nutrition and fluids is continued. These patients are not "terminally ill."

D. Persistent vegetative state patients do not have the capacity to experience pain or suffering. Pain and suffering are attributes of consciousness requiring cerebral cortical functioning, and patients who are permanently and completely unconscious cannot experience these symptoms.

There are several independent bases for the neurological conclusion that persistent vegetative state patients do not experience pain or suffering.

First, direct clinical experience with these patients demonstrates that there is no behavioral indication of any awareness of pain or suffering.

Second, in all persistent vegetative state patients studied to date, postmortem examination reveals overwhelming bilateral damage to the cerebral hemispheres to a degree incompatible with consciousness or the capacity to experience pain or suffering.

Third, recent data utilizing positron emission tomography indicates that the metabolic rate for glucose in the cerebral cortex is greatly reduced in persistent vegetative state patients, to a degree incompatible with consciousness.

II. The artificial provision of nutrition and hydration is a form of medical treatment and may be discontinued in accordance with the principles and practices governing the withholding and withdrawal of other forms of medical treatment.

A. The Academy recognizes that the decision to discontinue the artificial provision of fluid and nutrition may have special symbolic and emotional significance for the parties involved and for society. Nevertheless, the decision to discontinue this type of treatment should be made in the same manner as other medical decisions, i.e., based on a careful evaluation of the patient's diagnosis and prognosis, the prospective benefits and burdens of the treatment, and the stated preferences of the patient and family.

B. The artificial provision of nutrition and hydration is analogous to other forms of life-sustaining treatment, such as the use of the respirator. When a patient is unconscious, both a respirator and an artificial feeding device serve to support or replace normal bodily functions that are compromised as a result of the patient's illness.

C. The administration of fluids and nutrition by medical means, such as a G-tube, is a medical procedure, rather than a nursing procedure, for several reasons.

1. First, the choice of this method of providing fluid and nutrients requires a careful medical judgment as to the relative advantages and disadvantages of this treatment. Second, the use of a G-tube is possible only by the creation of a stoma in the abdominal wall, which is unquestionably a medical or surgical procedure. Third, once the G-tube is in place, it must be carefully monitored by physicians, or other health care personnel working under the direction of physicians, to insure that complications do not arise. Fourth, a physician's judgment is necessary to monitor the patient's tolerance of any response to the nutrients that are provided by means of the G-tube.

2. The fact that the replacement of nutrients into the tube is itself a relatively simple process, and that the

feeding does not require sophisticated mechanical equipment, does not mean that the provision of fluids and nutrition in this manner is a nursing rather than a medical procedure. Indeed, many forms of medical treatment, including, for example, chemotherapy or insulin treatments, involve a simple self-administration of prescription drugs by the patient. Yet such treatments are clearly medical and their initiation and monitoring require careful medical attention.

D. In caring for hopelessly ill and dying patients, physicians must often assess the level of medical treatment appropriate to the specific circumstances of each case.

1. The recognition of a patient's right to self-determination is central to the medical, ethical, and legal principles relevant to medical treatment decisions.

2. In conjunction with respecting a patient's right to self-determination, a physician must also attempt to promote the patient's well-being, either by relieving suffering or addressing or reversing a pathological process. Where medical treatment fails to promote a patient's well-being, there is no longer an ethical obligation to provide it.

3. Treatments that provide no benefit to the patient or the family may be discontinued. Medical treatment that offers some hope for recovery should be distinguished from treatment that merely prolongs or suspends the dying process without providing any possible cure. Medical treatment, including the medical provision of artificial nutrition and hydration, provides no benefit to patients in a persistent vegetative state, once the diagnosis has been established to a high degree of medical certainty.

III. When a patient has been reliably diagnosed as being in a persistent vegetative state, and when it is clear that the patient would not want further medical

treatment, and the family agrees with the patient, all further medical treatment, including the artificial provision of nutrition and hydration, may be forgone.

A. The Academy believes that this standard is consistent with prevailing medical, ethical, and legal principles, and more specifically with the formal resolution passed on March 15, 1986 by the Council on Ethical and Judicial Affairs of the American Medical Association, entitled "Withholding or Withdrawing Life-Prolonging Medical Treatment."

B. This position is consistent with the medical community's clear support for the principle that persistent vegetative state patients need not be sustained indefinitely by means of medical treatment.

While the moral and ethical views of health care providers deserve recognition, they are in general secondary to the patient's and family's continuing right to grant or to refuse consent for life-sustaining treatment.

C. When the attending physician disagrees with the decision to withhold all further medical treatment, such as artificial nutrition and hydration, and feels that such a course of action is morally objectionable, the physician, under normal circumstances, should not be forced to act against his or her conscience or perceived understanding of prevailing medical standards.

In such situations, every attempt to reconcile differences should be made, including adequate communication among all principal parties and referral to an ethics committee where applicable.

If no consensus can be reached and there appear to be irreconcilable differences, the health care provider has an obligation to bring to the attention of the family the fact that the patient may be transferred to the care of another physician in the same facility or to a different facility where treatment may be discontinued.

D. The Academy encourages health care providers to establish internal consultative procedures, such as ethics committees or other means, to offer guidance in cases of apparent irreconcilable differences. In May 1985, the Academy formally endorsed the voluntary formation of multidisciplinary institutional ethics committees to function as educational, policy-making, and advisory bodies to address ethical dilemmas arising within health care institutions.

IV. It is good medical practice to initiate the artificial provision of fluids and nutrition when the patient's prognosis is uncertain, and to allow for the termination of treatment at a later date when the patient's condition becomes hopeless.

A. A certain amount of time is required before the diagnosis of persistent vegetative state can be made with a high degree of medical certainty. It is not until the patient's complete unconsciousness has lasted a prolonged period—usually 1 to 3 months—that the condition can be reliably considered permanent. During the initial period of assessment and evaluation, it is usually appropriate to provide aggressive medical treatment to sustain the patient.

Even after it may be clear to the medical professionals that a patient will not regain consciousness, it may still take a period of time before the family is able to accept the patient's prognosis. Once the family has had sufficient time to accept the permanence of the patient's condition, the family may then be ready to terminate whatever life-sustaining treatments are being provided.

B. The view that there is a major medical or ethical distinction between the withholding and withdrawal of medical treatment belies common sense and good medical practice, and is inconsistent with prevailing medical, ethical, and legal principles.

C. Given the importance of an adequate trial period of observation and therapy for unconscious patients, a family member must retain the ability to withdraw consent for continued artificial feedings well after initial consent has been provided. Otherwise, consent will have been sought for a permanent course of treatment before the hopelessness of the patient's condition has been determined by the attending physician and is fully appreciated by the family.